

Patient reported outcome measures in physical activity interventions for people with dementia

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Aims: To identify all patient reported outcome measures (PROMs) used in physical activity interventions for people with dementia. This study will inform the development of Core Outcome Set to evaluate physical activity in people with dementia.

Methods: A systematic mixed studies review was conducted. Quantitative, Qualitative and mixed methods studies with a focus on physical activity for people with dementia were sought. Only studies published from 2005 onwards, and written in English, Spanish or Portuguese were included. No restrictions were made regarding intervention setting or stage of disease progression.

All PROMs were identified from the methods and results sections of the included papers. A content analysis approach was used to demonstrate the most frequently used PROMS per stage of disease progression.

Results: 140 studies from 22 different countries were identified, of which 56 used PROMs as measurements of their interventions. The 41 different PROMs identified were used to measure outcomes related to “personhood” (such as self-esteem, quality of life or self-efficacy), “behavioural and psychological symptoms of dementia” (such as depression, anxiety and sleep), overall levels of physical activity, mood and pain. The majority of studies using PROMs included patients in the earlier stages of the disease.

Conclusion: A large variety of PROMs was identified in the assessment of physical activity interventions for people with dementia, reinforcing the need for a Core Outcome Set in this area. Future research is needed in the use of PROMs in the later stages of dementia.